

Need for formal bereavement support in dementia care is largely underestimated

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The need for grief counseling in dementia care may be substantially underestimated, according to new research led by a UCL academic.

The study into levels of pre-death grief for caregivers of someone with dementia found that the need for formal counseling was around 300% higher than current predictions.

The new *International Journal of Geriatric Psychiatry* paper was supported by the end of life charity Marie Curie.

The current public health framework model for [bereavement](#) care states that most people will adapt to loss through [support](#) from their social network but suggests that 10-12% of people will require professional support.

However, this new study found that 30% of dementia caregivers needed professional support.

The paper describes pre-grief as the caregiver's response to "perceived losses in a valued care recipient", adding that, "Family caregivers experience a variety of emotions (e.g. sorrow, anger, yearning and acceptance) that can wax and wane over the course of dementia, from diagnosis to the end of life."

Lead researcher Kirsten Moore, who completed the study while based at the Marie Curie Palliative Care Research Department, UCL Psychiatry, said, "Our research showed that 78% of those caring for someone with dementia reported experiencing pre-death grief. The participants cited that finding the right person to talk to wasn't always easy and that some feel they can't access bereavement services as the person is still alive.

"We can see that the current bereavement models may underestimate the level of formal counseling and support these caregivers need and that services are under-resourced to meet the demand, meaning people are going without much-needed support. These caregivers provide vital care to people living with dementia, and they have a right to access

appropriate support for their own well-being."

Deborah Paget, 61, is a retired nurse who cared for her mother, Audrey, when she was diagnosed with vascular dementia and Alzheimer's.

Deborah says, "When I was caring for my mum, I found there was nothing in terms of support for pre-grief, there was no framework, no structure, nothing. I was in deep mourning for my mum, and I didn't know how to reach out to anyone for emotional support

"The grief I experienced before she died, compared to after, was so different and I felt so unprepared. Looking back, I should have tried to reach out but when you are caring for someone, you need to be encouraged to reach out for support. There needs to be a structure in place that signposts you to the support you need. After my mum died, I was so overwhelmed, and I felt so lost and alone. With a bit more support to manage my grief, while she was still here, perhaps I would have been able to cope just a little better."

Marie Curie says change is needed urgently, not just to meet the current need but to ensure that bereavement services are ready to meet the increased future needs of the UK's aging population.

Rachel Warren, Senior Policy and Research Manager at Marie Curie, and researcher on the UK Commission on Bereavement, says, "Caring for a loved one with dementia can be a lonely and distressing experience. When someone mourns a loved one who is changing every day they can experience grief for the person who is still alive."

"Without appropriate support some caregivers are at risk of later experiencing prolonged grief disorder which can have a detrimental impact on their well-being. We know from the findings from the UK Commission on Bereavement that being well supported before and during a death is vital to how someone copes when the death occurs."

"The number of people living with Alzheimer's is increasing with the aging population, so we urgently need to ensure better support is in place for caregivers. If the Government invested just the equivalent of a pint of milk for each person in the population, it would help to transform the availability and accessibility of bereavement support to those who need it."

The UK Commission on Bereavement, an independent commission launched in June 2021, looked at the experiences of people who had been bereaved over the past five years. Based on the findings, it made eight key recommendations for a vision for bereaved people in the future. These included being well supported before and during the death, and to be able to easily find and access the right emotional bereavement support that suits their circumstances.

Dr. Richard Oakley, Associate Director of Research at Alzheimer's Society, said, "This study shows what we see every day on our Dementia Support Line—we desperately need an improved, better-resourced grief and bereavement support system that not only supports [caregivers](#) at end of life but in the case of dementia, from diagnosis onwards."

"For a [caregiver](#), strong feelings of grief can arrive well before a person living with dementia reaches the end of their life, as there is a loss of a shared future and intended relationship and lifestyle."

"These feelings may develop or change as the person's dementia progresses and can start when they first notice they are unable to do the same things they used to, when they are diagnosed, or at any other point while they're living with the condition. While family and social networks play an important role in providing support, this research shows that these networks alone are often not enough."

"With dementia cases set to rise to 1 million by 2025, it's not acceptable

that families continue to face their [grief](#) alone. We need to have the right support available for families to support them along the whole [dementia](#) journey from diagnosis to end of life."

More information: Kirsten J. Moore et al, Exploring how family carers of a person with dementia manage pre-death grief: A mixed methods study, *International Journal of Geriatric Psychiatry* (2023). [DOI: 10.1002/gps.5867](https://doi.org/10.1002/gps.5867)

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